



Social Policy Research Centre Report Series

Never Stand Still

Faculty of Arts and Social Sciences

Self directed disability support (SDDS): building community capacity through action research

Research Plan

Karen R Fisher, Sam Cooper, Christiane Purcal, Ngila Bevan and
Ariella Meltzer

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or contact:

Publications, SPRC,
Level 2, John Goodsell Building
University of New South Wales,
Sydney, NSW, 2052, Australia.

Telephone: +61 (2) 9385 7800
Fax: +61 (2) 9385 7838
Email: sprc@unsw.edu.au

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Social Policy Research Centre, UNSW

Karen Fisher, Christiane Purcal, Rosemary Kayess, Ariella Meltzer, Sam Cooper, Deb Brennan

People With Disability Australia

Ngila Bevan

Centre for Children and Young People, Southern Cross University

Sally Robinson

Authors

Karen R Fisher, Sam Cooper, Christiane Purcal, Ngila Bevan and Ariella Meltzer

Contact for follow up

Karen Fisher or Christiane Purcal, Social Policy Research Centre, University of New South Wales, Sydney NSW 2052, ph: (02) 9385 7800 or email: karen.fisher@unsw.edu.au, c.purcal@unsw.edu.au.

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Abbreviations

CARD	Community action research disability group
CRPD	United Nations Convention on the Rights of Persons with Disabilities
DSS	Disability Services Standards
NDA	National Disability Agreement
NDIS	National Disability Insurance Scheme
NDS	National Disability Strategy
PWDA	People With Disabilities Australia
PWI	Personal Wellbeing Index
SCU	Southern Cross University
SDDS	Self directed disability support
SPRC	Social Policy Research Centre
UNSW	University of New South Wales

1 Introduction

Disability support has historically been organised and financially managed through government and service provider agencies (agency funding). Increasingly it is offered through individualised, person-centred packages of support (individual or self directed funding), which allow people to manage how their own funds are spent. Opportunities for self directed disability support (SDDS) – in both agency and individual funding approaches – are expanding across Australian states and territories, in line with the National Disability Insurance Scheme (NDIS) reforms.

This project explores how people with disability manage the transition towards self directed disability support. Australian evidence on this critical topic is thin. We know little about the impact of self directed options on people requiring support, informal carers and support providers (Prideaux et al 2009). Likewise, there is little systematic information about the effectiveness of existing disability support systems (Baxter et al 2010). Such information is gathered in this project, and it is important for assessing the impact of new approaches on equity of access, quality and availability of support, and community outcomes (Ungerson & Yeandle 2007).

The Social Policy Research Centre (SPRC), University of New South Wales (UNSW), in collaboration with People With Disability Australia (PWDA) and the Centre for Children and Young People (CCYP), Southern Cross University (SCU), is conducting the project. This plan explains the project methodology and management.

1.1 Project summary

This comparative study of the organisation of disability support across the Australian states and territories will develop an understanding of disability support from the perspective of people with disability. It will investigate the impact and effectiveness of changes to self directed options for people requiring support, informal carers and support providers. It will also be a formative baseline for a longitudinal study examining service delivery systems pre and post the introduction of the NDIS. The project is aligned with each of the directions, foundations and principles in the Disability Research and Development Agenda (Appendix 1 Disability Research and Development Agenda).

The findings will help to advance disability rights and the sustainable provision of effective, good quality social support. The findings can inform the development of self directed support policies, the responsiveness of disability support providers to the new policy landscape and the capacity of the disability community to use the opportunities presented by self directed supports.

This study uses a participatory action research approach. In line with the ‘nothing about us without us’ philosophy, participatory action research takes a collaborative approach in which researchers and people from the community work together to develop knowledge and effect change (Balcazar et al 2004). Participatory research views people as experts in their own lives. It aims to create knowledge that reflects what is important to the participants and that can be used to create change.

Action research methodology will be used to examine the impact of self directed disability supports on the rights of people receiving support and on the service system as well as to develop local capacity throughout Australia to maximise the effectiveness of the opportunities in the new support systems. In each state and territory, groups of people with disability (and their families/carers where relevant), supported by PWDA and university researchers, will collect the research data. This will build capacity within the disability community, strengthen peer support about self directed supports and develop research skills.

This action research process can empower people with disability to use the opportunities presented by the current policy changes: to improve the person-centred focus of support for people who already use individual funding, and to enable quality improvement for those who remain with agency funding.

2 Research framework

2.1 Aims and questions

The project is a national comparative study of the impact of self directed disability support (SDDS) at Commonwealth, state and territory levels. Research partnerships with disability community organisations in each state and territory will support the data collection and build research capacity among organisations, people with disability and their supporters.

Research question

How do changes towards self directed disability support impact on people using support and on the systems through which support is delivered?

The research is from the experience of people with disability. It focuses on:

- the rights of people affected (people receiving support through self directed and agency funding, informal carers and formal support providers) and
- the effectiveness of disability support systems regarding equity of access, quality and availability of support, individual outcomes and the community.

Research aims

The project aims to develop an understanding of disability support from the perspective of people with disability. This will:

- increase understanding of the impact of changes to disability funding on people receiving support, informal carers and formal support providers
- describe practical experiences of person-centred approaches to disability funding
- increase understanding of the mechanics, choices and implications of SDDS
- inform best practice for disability support services and policy, particularly about peer support for decision making about SDDS.

The project will also be a formative baseline for a longitudinal study examining disability support systems in the context of the introduction of the NDIS.

2.2 Participatory action research

Participatory action research is central to this project. It will be achieved through forming community action research disability groups (CARDs) comprised of people with disability who will collect the research data, through an advisory group and through inclusive workshops. The research is national with a local focus.

Community action research disability groups (CARDs)

CARDs will be formed in each state and territory and include people using disability support through self directed and agency funding arrangements, including people unable to access the support they need because of shortcomings in the current disability support system.

Group facilitators will encourage diversity in membership and research participation (gender, culture, location, age, support needs and socio-economic situation). Having local groups will enable diversity between the groups, depending on the local priorities, characteristics, strengths and needs. The groups are described in detail in Section 3.

A participatory action research approach underpins the design and work of the CARDS (Section 3.3). The aim is to share knowledge and build research capacity in the disability community by supporting groups of people with disability to generate information, participate in analysis, reflect throughout the project on this process and take action. Further, this process aims to build peer support for decision making about SDDS, and it will generate findings about best practice support to inform policy and service provision.

National advisers

National advisers from disability community organisations will be consulted at least twice via teleconference and e-mail, to advise on the research design, policy context, analysis, dissemination and follow up plans.

Inclusive workshops

Inclusive research attempts to maximise participation of people with a direct interest in the research topic. Inclusive workshops will be held locally and nationally: teleconference advice from national disability community organisations (as above); a CARD public activity in each location for members and the wider disability community; a training workshop for CARD facilitators (disability community organisations); and a national workshop associated with the Australian Social Policy Conference 2013 (ASPC).

The workshops will contribute to community capacity building, reflective practice, feedback and dissemination, as well as academic, policy and practice implications at the local and national levels.

3 Research methodology

3.1 Community action research disability groups

Community action research disability groups (CARDS) will be formed in each state and territory. CARDS will be coordinated by PWDA and facilitated by a local disability community organisation or key person. Each CARD will be comprised of approximately six people (and their supporters, if relevant) currently using disability support organised through self directed funding and approximately six people whose support is organised through an agency.

The CARDS have three functions: to stimulate reflection and discussion about self directed approaches to disability support; to increase local research capacity; and to generate research data (see below). Each CARD will be encouraged to facilitate a public event during the project, in order to broaden the development of inclusive disability research capacity and peer support for SDDS.

The SPRC, PWDA and SCU partnership will support the CARDS in their activities such as recruitment, publicity, research training and data collection. Resources for the facilitators will be adapted from the partners' previous disability inclusive research.

CARDS will use a range of data collection methods to support innovative ways of peer-supported learning and to enable the inclusion of a wide range of people with disability. The inclusive focus will also enable the extension of the project beyond the CARDS to other people with disability in the community, incorporating their views into the research.

CARD objectives

The outcomes for participants include:

- Knowledge sharing about disability supports from the life experiences of people with disability, with a focus on SDDS
 - Share good practice about self directed supports in general, specifically good practice occurring in the NDIS launch sites.
 - Discuss and experiment with the transferability of good practices.
 - Share bad practice or innovations that have not worked and question why.
- Capacity building
 - Build individual and group confidence for self-advocacy, community participation, challenging exclusion, responding to consultation opportunities and having policy input.
 - Increased political participation and potential to contribute to local, state, territory and federal policy processes, including those related to the design and implementation of the NDIS.
 - Understand human rights concepts and practices.

- Networking
 - Create a network of people with disability who share experiences about SDDS across Australia and can provide peer support and motivation.

Outcomes for PWDA include:

- Promotion of inclusive, self directed models of support, strengthening networks and membership, capacity building of people with disability.

Outcomes for UNSW and SCU include:

- Gathering and analysis of research data regarding SDDS, developing and strengthening disability inclusive research practices.

CARD participants

Card participants are:

- A local facilitator identified in each state and territory by PWDA. The facilitator will be paid for preparation time, facilitating meetings, writing meeting reports and posting to a project webpage. The facilitator and meeting expenses will be paid through PWDA.
- Approximately six people with disability (or family members of children with disability) who currently receive a self directed funding package and six who do not in each state and territory. The total number of participants nationally will be approximately 100. A variety of people will be encouraged to participate in the CARDS, including people who have less experience of participating in similar groups before, and people of different ethnic and language backgrounds, ages, genders, types of disabilities and levels of support needs.

CARD methods

CARDS will be encouraged to meet once a month during the project, approximately six times between May and October.

Each gathering is likely to be a two-hour facilitated meeting in which groups are encouraged to discuss their experiences of the month's research topic, discuss contributions from other CARDS and plan any activities between meetings. At the end of each meeting the group will fill in a template reflecting on the meeting, the action research process and what they think is the important and interesting information from the meeting.

Audio from CARD meetings will be recorded and sent to the SPRC, along with the completed templates and any visual data from the meetings (e.g. butcher's paper notes). The CARD facilitators will debrief from each meeting with PWDA and complete a template reflecting on the CARD process.

While not essential, CARDS will be encouraged to collect data from others in the community using innovative participatory methodologies. Any data from CARD research activities in the community will also be sent to the SPRC.

CARD members and potential community participants will be encouraged to complete two short surveys: a demographic survey and the Personal Wellbeing Index (PWI) (Cummins and Lau 2005).

Supporting the CARDS

CARD facilitators will be supported with training, resources and an online forum. Training will be conducted via a one-day workshop at the SPRC at the beginning of the project. The workshop will cover research skills and methodologies as well as research ethics considerations aimed at engaging participants without coercion and keeping personal information confidential. Resources provided to facilitators will include topic guides with prompts and discussion ideas, how-to guides for innovative research methods, and facilitation guides for including people with different types of disabilities and support needs. Resources can be developed in various accessible formats.

Communication between the CARDS, PWDA and the SPRC

PWDA will create a simple closed-group online forum for CARD facilitators and the researchers involved. Facilitators will post meeting reports and research experiences to this forum and can comment on the contributions of other CARD facilitators.

3.2 Data collection

Through establishing the CARDS, a national sample of at least 100 people who use disability support organised through self directed funding and agency funding will be recruited across all states and territories. This core sample from the CARD membership will extend to include additional community members, according to the activities of the local CARD.

Data will be collected about people's experience of disability support under both self directed and agency funding arrangements. The content will depend on the interests of CARD members and may include the organisation of support; experiences with person-centred planning, aspirations, supported decision making and support content; transition processes between agency and self directed funding; and outcomes.

Comparative standards for methodological design will include the UN Convention on the Rights of Persons with Disabilities (CRPD), National Disability Strategy (NDS), National Disability Agreement (NDA), Disability Service Standards (DSS) and future NDIS reforms. These standards will inform the methods in the project, including the topic guides and data collection.

Data collection methods will include validated quantitative outcome measures such as the Personal Wellbeing Index, as well as qualitative material from CARD meetings, reflective templates and CARD research in the community. Details of potential CARD research methods are in Appendix 2 Suggested CARD methodologies. The purpose of including a range of data collection methods is to support innovative ways of peer-supported learning and to enable the inclusion of a wide range of people with disability. The SPRC will support the data collection via training and resources (3.3).

SCU will provide advice on inclusive research methods, particularly regarding non-traditional narrative methodologies; the ethical engagement of children and young people; and the regional and rural participation of people with disability.

CARD research topics

During their six meetings, CARDS will discuss various aspects of their disability support. In the first meeting, they will agree on preferred topics and their sequence. All topics will relate to the overarching research question for CARDS: What are your experiences with your disability support, and what kind of support do you wish for? Below is a list of six relevant research topics that, as a whole, cover salient aspects of the research question. These topics are suggestions only and can be varied in content and sequence according to each CARD's preferences. However, the last meeting of each CARD should include a reflection on the research process and outcomes, as outlined below.

The six suggested research topics are:

- Characteristics of your disability support: flexibility, control, choice, self-determination, size of the package
- Access to information about what support is available, administration, help to manage funding packages, advocacy
- Participation in the community: employment and education, accommodation, health services
- Social life: Family and social networks, valued relationships, leisure, recreation
- Arrangements and relationships with support workers
- Reflection on the research process and outcomes: How have you found this process? What does it mean for disability support? What do you want to tell other people?

CARD facilitators will be encouraged to incorporate the two short surveys of CARD members – the PWI and demographic survey – into the first meeting and to repeat the PWI in the last meeting, in order to include a longitudinal aspect into the research.

3.3 Participatory action research

Participatory action research involves continuous reflection on the research content and process throughout the project. It aims to use the knowledge gathered to create change even as the research project continues. The changes intended by this project are: building research capacity in the disability community and strengthening peer support around SDDS.

Building research capacity

Research capacity in the disability community is built through:

- Training for CARD facilitators at the beginning of the project to build the research capacity of the facilitators themselves and, by extension, their organisations and the CARD members.

- Resources for CARD meetings, including: topic guides for discussion, guides on different research methodologies and advice on ethics considerations. Resources will be expanded and refined with feedback from facilitators and CARDS to make them useful for this and other projects.
- Additional resources for CARD members, developed by them (with advice from the university researchers, if requested) during the course of the project, e.g. surveys.
- CARD members using data collection methodologies with each other and people with disability outside of the CARDS.
- The CARD online forum, which will provide a space for facilitators to share ideas, issues and experiences about SDDS, conducting research and the CARD process. Ideas and good practice can be implemented by other CARDS during the project and in an ongoing way afterwards. CARD members will be able to read the online forum.
- Templates that the CARD facilitators fill in together with the CARD members after each meeting and distribute via the online forum will include their reflections on the meeting and the process – what worked well and what didn't?
- CARD facilitators will debrief after each group meeting with PWDA. This will help facilitators reflect on the process and on whether and how to adjust it.
- The last CARD meeting will focus on the learnings from the project including the research process, and on what to do next.
- Research findings will be disseminated in accessible formats.
- As far as project resources allow, additional ways of building research capacity will be included as suggested by CARD members and facilitators throughout the project.

Strengthening peer support around SDDS

Peer support around SDDS is strengthened through:

- CARD members getting to know each other and sharing information about disability funding.
- The CARD community events, which will help disseminate CARD experiences with disability funding and enable CARD members to strengthen their networks.
- The facilitator training and the online forum will provide opportunities for the CARD facilitators to develop peer support networks and connections for their local disability organisations.
- At the beginning of the project, CARD facilitators and researchers will explore ways for CARD members from different groups to develop networks and share knowledge directly, for example via an online platform. Privacy and confidentiality need to be considered.

- The CARDS and communication strategies in the project are set up with a local focus and easy access, as they are intended to enable ongoing contacts and networks between research participants after the project.

Reflecting on the research process

Participatory action research is reflexive and therefore involves continuous assessment and adaptation of the research process. Methodologies will be refined as the project progresses, and it is expected that learnings for future projects will emerge.

Reflection will focus on how well the research and engagement processes work: What helps or hinders participation of people with disability in the project? How do the resources and training help? What can be improved? How can research experiences be made useful to future projects?

In this project, the methods used for reflecting on the research process are:

- Short templates filled in by CARDS after each meeting.
- Debrief of CARD facilitators with PWDA after each session.
- The last CARD session should include thorough reflection on the research process.
- The web forum will provide a reflection space for CARD facilitators.
- Researchers will reflect on the process at regular meetings and will support CARD facilitators in refining the process.

4 Data analysis

4.1 Framework for data analysis

The qualitative and quantitative data will be analysed against the research question, comparing by jurisdiction (state and territory), type of support arrangement and characteristics of the person. The conceptual framework, common to all the data collection and analysis, is derived from the comparative standards for change in outcomes from the CRPD, NDS, NDA, DSS and NDIS (material standard of living; participation, growing and learning; health and wellbeing; social relationships; autonomy; whole of life). We have applied this framework in similar research about rights outcomes and service effectiveness. The framework can accommodate the rich qualitative and quantitative data, without compromising the integrity of individual stories or service system information.

Input and feedback from CARD facilitators, both on the research questions and process, will contribute to data analysis as part of the participatory action research approach.

4.2 Expected outcomes

Expected outcomes are:

- Local disability support and research capacity development for people with disability, their families/carers and disability community organisations.
- Formative baseline data about the experiences of a national sample of people using disability support organised through self directed funding or agency funding.
- National report and journal articles.
- Resources for local community action research disability groups.
- National and local web-based resources and narratives.
- Australian Social Policy Conference September 2013 special workshop.
- ARC Linkage grant application for a cohort study.

4.3 Potential findings

Potential findings relate to the research question and the participatory action research methodology and build on our earlier outputs (Fisher et al 2010; and Section 4.1). We expect that the research process will lead to capacity building among people with disability, their families/carers and advocates.

Findings about the organisation of SDDS will inform processes, infrastructure and cultural change in the community to:

- learn about the practical experiences of person centred approaches to disability funding;

- increase understanding of the mechanics, choices and implications of SDDS;
- provide people with peer support for decision making; and
- enhance the capacity of individuals and groups to act on their preferences about disability support.

The participatory action research process will inform future research projects generated by local community organisations and academics. Successful aspects of the methodology will be used for the longitudinal research.

Implications for policy development and service delivery

The findings have policy and practice significance for disability community members, government and nongovernment agencies concerned with disability rights and the sustainable provision of effective, good quality social support. The practical implications will be local capacity building in peer-supported decision making and national lessons to improve the way people with disability and their supporters engage with funding choices.

In addition, the project will inform formative baseline data for a longitudinal study, which will generate evidence for effective policy making and service provision.

Local research capacity building will inform further local activities and national collaboration on topics such as peer-supported decision making; cooperation between informal and formal supporters; sustainable local financial management strategies; sharing SDDS experiences with people who are less familiar with service systems; and engaging hard to reach populations.

4.4 Limitations of findings

Limitations relate to the short timeframe and limited budget. Participatory action research is resource-intensive, however the available time and budget of this project restrict the number, and therefore diversity, of people participating and the depth at which they can become involved. For these reasons the CARDS have been designed as baseline groups with a formative focus, in the hope that they will continue to function and inform SDDS practice after the end of the project.

Since the focus of time and budget is on formative research activities, the amount of quantitative data collection has been minimised, which restricts comparison beyond the sample. This limitation has been addressed by incorporating mixed methods with validated quantitative instruments and a conceptual framework from national and international standards, so that the results can be generalised and repeated.

5 Project management

5.1 Project timeframe

		Month
Design		
Contact national advisers	UNSW	March
Finalise CARD resources for training, support and data collection tools	UNSW	March
Ethics application	UNSW	March
Facilitators confirmed and briefed re administration of finances	PWDA	March
Facilitators trained	UNSW	March
Knowledge generation		
Convene local CARDs approx monthly	Facilitators	May - Oct
Facilitators supported	PWDA	April - Oct
Ongoing data collection at CARD events and in-between	UNSW	May - Oct
Local CARD public event		May - Oct
Data analysis	All	Oct
Final CARD meeting, evaluation, next steps	PWDA	Oct
Knowledge transfer		
Advisory group – telephone, ongoing		April - Oct
Australian Social Policy Conference special workshop		Sept
Outputs – public reports, CARD resources, academic		Dec
Dissemination and project follow up in multiple formats		Jan
Post project		
Continued CARD activities through community engagement		2014
Australian Research Council application for longitudinal follow up		2014
Longitudinal research if ARC successful		2015

5.2 Project team

Project leaders	Karen Fisher and Christiane Purcal
CARD coordinator	People With Disability Australia – Ngila Bevan
Design, collection and analysis	Ariella Meltzer and Sam Cooper
Inclusive methods advice	Sally Robinson and Rosemary Kayess
Social service system advice	Deborah Brennan

Appendix 1 Disability Research and Development Agenda

The project is aligned with each of the directions, foundations and principles in the agenda.

DIRECTIONS

• **Disability related social and economic inclusion research, including research which focuses on human rights, participation in community life, access to mainstream activities and services, and broader systems change.** – The project addresses all points. Social and economic inclusion is an important goal of self directed disability support policies. Our research findings will provide evidence for policy makers to tailor policies, and will assist people with disability to use support options, so that inclusion can be enhanced.

The project explores how people's disability rights are affected by the current policy shift to self directed funding, including their participation in community life and access to mainstream services.

A central aspect of the research is investigating changes in the disability support system regarding its effectiveness to provide equitable, quality support.

• **Evaluations, reviews and research to contribute to the evidence base to improve service delivery and support options.** – The research will provide evidence on how various disability service and support options affect people and service providers, with the goal to improve services to better meet people's needs.

• **Analysis of the factors that support sector sustainability, sector development and improved organisational capability.** – Service providers will participate in the research, so that the study can identify factors to enhance providers' ability to adapt to policy changes and remain viable.

• **Research on the profile, experiences and issues affecting diverse and/or disadvantaged groups of people with disability.** – The study is designed around local disability community groups in each state and territory, and it will include participants from diverse demographic, cultural, socio-economic and geographic communities (see CARD description below). For example, the Northern Territory has large remote areas, lack of services and a significant Indigenous population. Different environments influence people's access to, and experiences with, disability support. A goal of this project is to explore these different experiences and, through the action research process, build capacity in disability communities to enhance people's ability to use the opportunities presented by self directed support.

FOUNDATIONS

• **Research and development partnerships and collaborations within the disability sector, with people with disability, and with other relevant sectors and disciplines** – The project will be conducted in partnership between the SPRC, PWDA and SCU. This research partnership has been active for over 10 years, collaborating successfully on numerous research studies and capacity building events (see CVs). In the project, PWDA will coordinate the local disability

organisations in each state and territory to establish community action research disability groups (CARDs), which in turn will involve other local disability groups and individuals. SCU will advice on inclusive research with people with disability in regional and rural areas, and children and young people, and using non-traditional research methods.

• Inclusion of disability issues within mainstream Australian research funding and activities, building effective participation of people with disability and the adoption of methodologies that support their involvement – Research

participation of people with disability is central to the methodology of this study. People with disability will form local community action research disability groups (CARDs) and collect primary data for the study, through interviews, surveys and other data collection methods that the CARDs decide on. These will include social media, photos or voice recordings. A variety of innovative data collection methods will ensure that people with a wide range of disabilities can participate in the research. The CARDs' activities in data collection will also build research capacity among the disability community, to encourage the generation of local research projects. The project partnership will form the basis for follow-up applications to ARC, government and other funding streams.

• Accessible disability related research and data and application of evidence-based findings and approaches in practice – The SPRC, PWDA and SCU have extensive expertise in producing accessible research documents. For example, recent SPRC projects that produced easy read documents were: ARTD Transition to Retirement, FaHCSIA Easy Read advocacy documents, and ADHC Supported Living.

IMPLEMENTATION OF THE NDA, NDS AND NDIS

The intention of current and future reforms is to promote and facilitate the rights, outcomes and inclusion of people with disability in a range of ways – through specialist support, access to general community activities, and fostering of rewarding relationships. This research contributes directly to this central aim through formative action research to change practice, and by measuring impact, effectiveness and improvement of the key strategies used to fulfil this aim, from the perspective of those who use the programs.

The research pertains particularly closely to the NDS priority areas for action about personal and community support, and health and wellbeing. The comparative standards in the conceptual framework are derived from these policy initiatives. The rationale for the framework is that the research can form a baseline experiential profile of the changes towards the individualised service approach in reforms such as NDIS. This will be important for informing equitable, quality service improvement as the reforms progress. Details of the policy implications are described in the research project.

TRANSLATING INTO POLICY AND PRACTICE

The study will provide new evidence of the impact of shifts in policy and practice on the lives of people with disability. This may inform the development and refining of policies and programs. Research findings will be translated into policy and practice

and contribute to the national and international evidence base through the multiple dissemination activities included in the project design (see details project).

Consistent with the inclusive and formative action research design, the translation into practice will begin within the project itself through the activities of the local CARDs, workshops for all participants (people with disability, supporters, disability organisations, service providers, government and other researchers), formal reports and articles in multiple accessible formats. The inclusive design means that findings related to self directed disability funding, peer support, decision making and community-generated research projects can be translated into practice during the project.

In addition, a framework for continuing the activities after the project finishes has been incorporated into the design.

This national project with local activities will ensure that findings specific to the location can be generated and implemented.

ADDRESS GAPS IN DISABILITY RESARCH

The research will address gaps in disability research about self directed supports in Australia. We do not have evidence about how the current policy change towards self directed funding impacts on the rights of people affected – people needing support, informal carers and support providers – or on the effectiveness of the disability support system.

We propose to fill this gap by using inclusive research methodologies, resulting in a growing capacity in communities across the country for people with disability to undertake research on topics of importance in their lives. The action research approach ensures that local CARDs will focus on the gaps relevant to their local communities, such as the service system context and capacity.

In this way, the research will address the gap identified in earlier activities of this research team (DIRC – see above), of limited local capacity for community generated research (see project for details).

Appendix 2 Suggested CARD methodologies

CARDs will investigate the experiences and aspirations that people with disability have with both self directed funding and agency funding, using the following or similar participatory methodologies.

Photo interviews

In photo interviews the interviewer presents the participant with photos and asks questions about these photos. Ideally photos will 'break the frame' – present a new view of normal things – to provoke reflection (Harper, 2002).

Photo interviews can create a less formal interview and provide space for the participant to direct the interview by choosing which photos to speak about, which part of the photo to speak about, or to talk about things outside the photo (Epstein et al., 2008). Photo interviews are useful for making abstract concepts more accessible (Hurworth, 2003). They can reduce the feeling of being tested or needing to choose the 'right' answer, reducing yes/no answers and acquiescence (Folkestad, 2000).

Photovoice

Photovoice gives cameras to people to document their lives, communities and what is important to them. These photos are then discussed in groups and priority issues identified. These priority issues guide data analysis, and summaries of the research are distributed widely in the community and presented to policy makers to create change (Novek et al., 2012). Photovoice aims to give people the ability and opportunity to record and create change in their communities rather than be passive subjects of others' research and intentions (Wang and Burris, 1997).

CARDs may adapt the philosophy of Photovoice to other media, such as painting, or selecting various important objects that represent their experiences and aspirations about self directed support (e.g. a bill from a restaurant they were able to attend with their new support staff).

Go-along interviews

Go-along interviews are in-depth qualitative interviews in which researchers accompany individual participants on natural everyday trips. This provides scope to investigate people's perceptions and navigation of their physical and social environments. The interviewer can ask questions about salient features of the environment, or leave it to the participant to talk about their usual experiences on routine trips and whatever comes to mind while looking at and moving through places. Interviews take about one hour to 90 minutes (Kusenbach, 2003).

Cards may also choose to use

- Discussions

- CARDs may choose to informally discuss a topic. This could be simply discussing their opinions or experiences, or using a more structured

format, such as *projective discussion*, where they say what they would like to happen in the future and discuss what is needed to get there.

- **Interviews**

- CARD members may choose to interview each other or people outside the CARD in an informal way and either report back on this to the group or make a more formal record through voice or video recording.

- **Surveys**

- CARDS will determine what information they want to find out in a survey, and researchers from the SPRC will advise on survey structure and questions. CARD members will complete the survey and may ask community members, service personnel, or other people with disability to participate also.

- **Focus groups**

- CARDS will determine which questions they wish to discuss as a group or invite other members of the community to join the focus group with them. In a CARD meeting, a focus group could be run by the facilitator, or CARD members could take turns running a focus group in successive months.

- **Technological methods**

- A range of technological methods could be used by CARDS, including voice or video recording and iPad apps, to record and organise information, either during or between CARD meetings.

- **Visual methods**

- A range of visual methods could be used by CARDS to present their opinion on the research topics, including artwork (e.g. painting, drawing, collage), timelines, mind maps or community mapping (i.e. drawing a map of what they access in the community with the assistance of their support services).

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